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Epilepsy stigma: Moving from a global problem to a global solution

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After thinking long and hard about what to include in this piece, I felt it was important to start with some examples of the negative attitudes and sometimes unbelievable ignorance that has and still does exist towards epilepsy. People are often unwilling to acknowledge the stigma that still exists towards one of the world's most common neurological conditions, one that can affect anyone of any age, shape or size. Epilepsy is not a single condition, nor is having epilepsy the same experience for all, but sadly, throughout the ages, it has caused much heartache for many of those affected by it. Fortunately, things are now a lot better, but if we look at epilepsy across the ages and throughout the world, we can appreciate both the progress that has been made and what still needs to change.

First, then, some anecdotes from history. In ancient Rome, if a person with epilepsy touched you, you were considered unclean, and had to spit to cleanse yourself of the demons that were transferred to you. In Babylon, according to their ancient text book, Sakkiku, written around 500BC, epilepsy was thought to be caused by ghosts and demons, and the Babylonians used exorcism, enemas, and amulets to cleanse the body. Likewise, in India in 1500–800BC, treatment was directed at cleansing the body, using enemas, purges, and vomitations. In 1770, a group of Chinese physicians composed a book "Huang De Nei Ching" which first documented information on epilepsy referring to it as a psychosis and a form of mania. They classified the severity of the seizure according to whichever animal sound they thought emitted by the person having it, i.e. horse, chicken, pig and so on. It was, however, Hippocrates the Greek physician, who wrote the first book on epilepsy, entitled "The Sacred Disease" in around 400BC. Hippocrates recognised that epilepsy was a brain disorder and was one of the first to speak out against beliefs that seizures were a curse from the gods and that PWE held the power of prophecy. Sadly, many people and cultures held onto very negative beliefs about epilepsy, so that in 1494 two Dominican friars wrote "Malleus Maleficarum" a hand book on witch-hunting, in which they claimed that one way to identify a witch was by the presence of seizures.

With regard to treatments for epilepsy, coal was long thought to have healing properties, as was coral, rubbed onto the gums, and hung around children's necks. Elder and mistletoe were also thought to have healing properties. My favourite old fashioned remedy goes back to the 17th century, when you were counselled to take a live mole, prick it with a pin, and sprinkle a few drops of its blood into a wineglass full of water. The Navajo Indians in the US believed that putting an iron nail in the spot where the head of the PWE fell would rid them of their seizures.

Some of the ideas about treatment of people with epilepsy throughout history help to highlight the extent of the humiliation and abuse they have suffered over the centuries. How much people with epilepsy must have prayed that the next potion or lotion would finally offer them a cure. In many societies, people with epilepsy were deemed damaged goods, imperfect and needing to be locked up in asylums. In 4th century BC Athens, slaves had to have their epilepsy declared at the time of their sale; and in ancient Babylon slaves with epilepsy could be returned with a full refund as damaged goods. Much closer to present times, laws were enforced in many countries that prevented people with epilepsy from marrying or having children, and also insisted on their sterilisation, since epilepsy was thought to be hereditary. People with epilepsy continued to be sterilised up to the 1930s in both Germany and the US.

So, what about the present day? As a person with epilepsy, I myself have come across significant prejudice in the workplace, losing several jobs over the last 25 years. I am not alone in having this experience. A friend of mine with epilepsy has recently been told that he is barred from working as a teacher until his seizures stop, as he is "frightening the children!" Even if, over the last 60 years, things seem to have improved regarding attitudes towards epilepsy, the following definition of epilepsy in a dictionary published in the 1960s still made me frown:

> A chronic functional disease of the nervous system, manifested by recurring attacks of sudden insensibility or impairment of consciousness, commonly accompanied by peculiar convulsions (Newnes Family Dictionary, 1960 Edition)

Sadly, a common thread running through almost every discussion amongst people with epilepsy about how it affects our lives is that the problem lies with society in general, and not those who live with the condition. Even though here in the UK, the Disability Discrimination Act came into force in 1995, there are still many problems with employment, and it would appear that, even in developed countries like the UK and the USA, people with epilepsy are often mistreated and forced to claim and live on disability benefits. In my experience, almost all would gladly start work tomorrow, if employers were not so ignorant and prejudiced towards their condition.

I want to look now, however, at how things have improved globally. First of all, how thankful we must be for modern medicine and all that entails, including anti-convulsant drugs, specialist

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hospitals, diagnostic techniques such as EEG, MRI, CT and PET scans, and of course, brain surgery. Drug treatment options are improving all the time, with new AEDs being developed with fewer or even no obvious side effects.

With the arrival of the internet the world is now a much smaller place, and for me being a member of several groups, talking to other people with epilepsy worldwide and sharing experiences with each other has been very therapeutic. For example, following two lots of surgery, I have 'talked' to many people waiting for surgery and others who have also had it. The internet has been a great medium for this. Thanks to Facebook and Twitter, people worldwide are now talking about their epilepsy – I myself talk regularly to people in India, Australia and US, and find getting a worldwide perspective fascinating. Some countries still have a long way to go with regard to epilepsy, but things are improving globally all the time, and increasingly we are seen as people with epilepsy who are as capable as anyone else.

People with epilepsy must keep on talking, not only amongst ourselves, but also to the rest of the world, and must keep raising awareness and educating other people. There is still a considerable degree of ignorance in the general population, even if for people with epilepsy personally there is a lot more help and support. I am constantly amazed at the different perceptions of epilepsy in different countries. Recently a person in the US wrote to me, telling me that his local Pastor had offered to come to his house and perform a private exorcism, to "rid him of his demons", the cause of his epilepsy. This person wanted my opinion as to whether he should go ahead with the exorcism – you can, I'm sure, imagine my reply!

Of course, people with epilepsy in the UK, and increasingly worldwide, also have access to organisations like Epilepsy Action, about to celebrate 60 years of helping them and their families. EA has been an invaluable source of support to me personally over the last 25 years, and I have passed its details to many newly diagnosed people. In the UK, one week a year is designated National Epilepsy Week, and this year the focus for the week was on young people with epilepsy. The main message of the Week was that having epilepsy must not hold you back from what you want to do in life – and young people today have help lines, websites and much information available for them to help with this aim.

As a person with epilepsy, I will continue to strive to raise awareness of this incredibly misunderstood condition, despite being told that I 'don't look as though I have epilepsy'! I realise there is still a long way to go, but as long as the world keeps talking, I believe epilepsy will continue to move forwards from being a once global problem, to finding and maintaining a global solution.

Conflict of interest statement

None declared.